

# Helping patients to improve self management of diabetes

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*Heart* 2004;90(Suppl IV):iv36–iv38. doi: 10.1136/hrt.2004.037622

Research suggests that people with diabetes are poorly compliant with dietary and exercise recommendations, and that primary non-compliance with medication is common. Local research has shown that patients' beliefs about diabetes suggest little understanding of the seriousness of the disease in terms of increased mortality. Portsmouth Primary Care Trust, in collaboration with Portsmouth Hospitals NHS Trust, is developing a range of structured self management programmes to assist in helping people be clearer about how they can make changes that will reduce their risk of diabetes complications and cardiovascular disease. These programmes are delivered to groups of patients, rather than on a single patient basis.



There is a need for all health professionals to rethink current approaches to the concept of self management in chronic disease management. The growing shortage of both doctors and nurses, together with the fact that chronic diseases such as diabetes and cardiovascular disease account for a rising proportion of the workload of all health professionals, means that it is not feasible to continue providing care in the way we have in the past.

The National Service Framework (NSF) for diabetes includes a standard around the concept of patient empowerment. Standard 3 talks about engaging people in effective self management, and has become known as the empowerment standard.<sup>1</sup> The recent National Institute for Clinical Excellence (NICE) technology appraisal of the use of patient education models for diabetes recommended that structured education be made available to all people with diabetes at the time of initial diagnosis and then as required on an ongoing basis, based on formal and regular assessment of need.<sup>2</sup> Although the document found insufficient evidence to recommend a specific type of education or activity, it did suggest that education be provided by an appropriately trained multidisciplinary team to groups of people with diabetes, and that it should focus on self management training.

Too often, the advice that health professionals give to patients does not result in activity. In diabetes, as with other chronic diseases, many patients given a prescription do not even collect their drugs.

Recent research suggests that people with diabetes only follow dietary recommendations about 60% of the time, follow exercise recommendations 34% of the time, and follow foot care recommendations 47% of the time.<sup>3</sup> In addition,

data from the DARTS-MEMO collaboration showed that only one third of people with type 2 diabetes who were taking one tablet a day obtained enough prescription to enable them to take medication 90% of the time.<sup>4</sup> Such statistics provide the stimulus needed for health professionals to challenge current models of care delivery around self management.

Health professionals frequently talk about "empowering" patients. Yet it is important to understand that responsibility for self management lies not with health professionals but with the patients themselves. While many health professionals feel frustrated that patients appear to decline to take responsibility it is clear that nearly all decisions that affect patient outcomes are made by the individual—they have the responsibility. Furthermore, nearly all the consequences of these decisions accrue to the individual with the condition, as they have the complications.

Nearly all the barriers to effective self management lie not in our systems of care but in the individual's personal and social world. Health professionals need to accept that people make the best possible decisions for themselves given their perception of their situation – most patients have a life beyond their condition. All that health professionals can do is to help the patient start to make informed choices rather than ignorant choices.

## RETHINKING DIABETES CARE

Research work on patients' beliefs about type 2 diabetes carried out in four primary care centres led us to think about the content of the education programmes we were developing. This work suggested that 64% of newly diagnosed patients agreed they would have diabetes for the rest of their lives, while 76% of longstanding patients agreed. We found that 22% of patients believed that diabetes would not have much effect on their health, and that only 9% of people with either longstanding or newly diagnosed diabetes believed that their life would be shorter because of developing diabetes.<sup>5</sup> It is well known that life expectancy is shortened by around 20 years in patients with type 1 diabetes and by about 10 years in patients with type 2 diabetes, yet still people think about type 2 diabetes as "mild diabetes".<sup>1</sup>

**Abbreviations:** DARTS-MEMO, Diabetes Audit and Research in Tayside Scotland/Medicines Monitoring Unit; ICC, innovative care for chronic conditions; JIGSAW, juggling insulin goals for success and well-being; NICE, National Institute for Clinical Excellence; NSF, National Service Framework; UKPDS, UK prospective diabetes study

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It is clear that health professionals have to begin to convey the seriousness of this disease to patients.

Further local research involved asking the same group of patients which self care activities were most likely to reduce their risk of future complications and cardiovascular disease. Although it might be expected that patients would mention “healthy lifestyle” advice such as stopping smoking and eating a low fat diet, in fact the responses showed that most people believed that seeing a health care professional, for instance at the annual review clinic, would make the difference. This challenged us to reconsider our model of care delivery in diabetes.

We also looked at the behaviour of health care professionals in the consultation. Most of the published literature around consultation skills is focused on doctors. As a group of nurses and dieticians in a specialist centre, we assumed we must be more effective in our communications with patients. We tested this by recording videos and then administering a questionnaire both to ourselves and to our patients about the consultation.<sup>6</sup> We found that we completely disagreed with our patients on the issues discussed in that consultation 20% of the time and completely disagreed with our patients on the decisions made 21% of the time. Perhaps more importantly, given that the evidence around behaviour change is that we should agree goals with our patients, we found that 40% of the time we completely disagreed with our patients on the goals set.

Despite the fact that as nurses and dieticians working in a specialist centre we have had a great deal of training around empowerment and counselling and communication skills, we were clearly not using that consultation resource effectively.

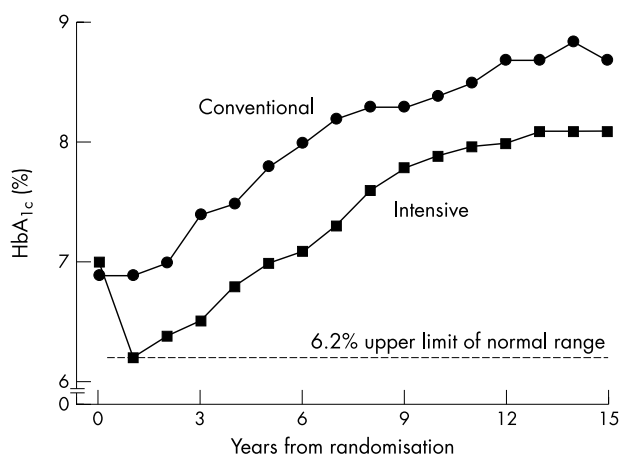
## LOCAL APPROACHES

In Portsmouth, we have now developed a range of structured group based self management programmes to help people with type 2 diabetes to be clearer about how they can make changes that will reduce their risk of diabetes complications and cardiovascular disease. We started with a whole day education programme on self management for newly diagnosed patients. This focuses on giving people information about their risks, explaining their “numbers”, helping people to understand their own beliefs about their diabetes and their cardiovascular risk, and then engaging them in an action plan.

This programme has now been running for three years and the evidence is that it is working. We have now started, with three surgeries, using group follow up instead of the usual one-to-one follow up. It is well known from studies such as the UK prospective diabetes study (UKPDS) that there is a progressive decline in patients’ control of blood pressure and serum glucose and lipids, despite regular visits over a number of years to health care professionals working to protocols (fig 1).<sup>7</sup> One study from Turin, in which the doctor and nurse followed up their patients every 3–6 months by means of group visits, suggested that it is possible to buck this trend. After two years, HbA<sub>1c</sub> concentrations were lower in patients seen in groups than in control subjects ( $p < 0.002$ ).<sup>8</sup>

Engaging with patients in a group situation appears to be beneficial. This may be due to peer pressure, or the fact that it is possible to give patients more time if they are seen in a group of 6–8 people than if they are seen individually for 10, 20, or even 30 minutes.

We have also developed a range of other programmes, which are all based on group education. These have included a programme for patients with type 1 diabetes entitled “Juggling insulin goals for success and well-being” (JIGSAW), a newly diagnosed type 1 structured group, and a starting insulin programme. We also are developing a



**Figure 1** The UK prospective diabetes study (UKPDS) showed a progressive decline in patients’ control of blood glucose. Adapted from UKPDS 33<sup>7</sup> with permission.

programme that focuses on self management of hypertension for patients with diabetes.

As health care professionals are trained it is important that we provide them with the skills needed to facilitate groups within surgeries. Within general practice there may be an issue about space, but as new surgeries are built it should be possible to plan for group rooms.

## THE WAY FORWARD

The World Health Organization’s innovative care for chronic conditions (ICCC) framework has highlighted a number of failures of current health services with respect to chronic conditions.<sup>9</sup> Too often they are organised to provide acute illness care, the patient’s role in management is not emphasised, follow up is sporadic, community services tend to be ignored, and prevention is under-utilised.

The ICCC framework presents a road map for organising health care for chronic conditions. It states that prepared, informed, and motivated patients and families:

- need to be informed about their chronic conditions, including the expected course, expected complications, and effective strategies to prevent complications and manage symptoms
- need motivation to change and maintain daily health behaviours, adhere to long term therapies, and self manage their conditions
- need to be prepared with behavioural skills to manage their conditions at home.

## CONCLUSION

The NSF for diabetes includes a standard around the concept of patient empowerment, and the recent NICE technology appraisal recommends that structured education be made available to all people with diabetes, at the time of initial diagnosis and then as required on an ongoing basis. It suggests that education be provided by a multidisciplinary team to groups of people with diabetes, with a focus on self management training. At Portsmouth, we have developed a range of structured group based self management programmes to help people with type 2 diabetes to understand how they can make changes that will reduce their risk of diabetes complications and cardiovascular disease. Engaging with patients in a group situation appears to be beneficial.

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